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Quality of dying and death in the ICU. The euroQ2 project

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ABSTRACT

Purpose: Knowledge of families' perspective of quality of intensive care unit (ICU) care is important, especially with regard to end-of-life (EOL) care. Adaptation of the US-developed "Quality of dying and death questionnaire" (QODD) to a European setting is lacking. The primary aim of this study is to examine the euroQODD's usability and its assessments of EOL care in a cohort of Danish and Dutch family members.

Methods: Family members of patients dying in an ICU after a stay of at least 48 h were sent the euroQODD three weeks after the patient died. Selected patient characteristics were obtained from hospital records. A total of 11 Danish and 10 Dutch ICU's participated.

Results: 217 family members completed the euroQODD part of the euroQ2 questionnaire. Overall rating of care was high, a median of 9 in Netherlands and 10 in Denmark on a 0–10 scale ($p < 0.001$). The Danish were more likely to report adequate pain control all or most of the time (95% vs 73%; $p < 0.001$). When decisions were made to limit treatment, the majority of family members agreed (93%). Most (92%) reported some participation in the decision-making, with half (50%) making the decision jointly with the doctor. About 18% would have preferred greater involvement. Factor analysis identified a six-indicator unidimensional quality of dying and death construct with between-country measurement invariance. However, in its current form the euroQODD instrument requires modeling the six items as reflective (or effect) indicators, when they are more accurately conceived as causal indicators.

Conclusions: The majority of family members were satisfied with the quality of EOL care and quality of dying and death. They agreed with decisions made to limit treatment and most felt they had participated to some extent in decision-making, although some would have preferred greater participation. Addition of items that can be accurately treated as effect indicators will improve the instrument's usefulness in measuring the overall quality of dying and death.

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1. Introduction

Caring for the dying patient is part of critical care, and the quality of that care affects not only the patient but his/her family. As the primary goal of treatment switches from cure to comfort, families often

experience stress as they may be asked to participate in making difficult decisions to guide care and as they anticipate the loss of their loved one [1,2]. As ICU clinicians, we have an important responsibility for providing good end-of-life care to patients and their families. Reliable measurement of the quality of end-of-life care is crucial to identify what goes well and where improvements are needed.

Due to the severity of their illness, ICU patients are rarely able to provide assessments of the care they are receiving, and family members become surrogates for these assessments. Family members' assessments of the quality of patient care have been found to correlate well with patient assessments in non-terminal care, providing support for their use in evaluating end-of-life care provided to critically ill patients [2,3].

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Instruments designed for families to complete include those used to measure the perceived quality of ICU care in general such as the Family Satisfaction in the ICU (FS-ICU) [4]. Others focus on end-of-life care such as the Quality of Dying and Death (QODD) questionnaire developed in the US [5]. The QODD has previously been tested in the Netherlands [6]. Several items had a high rate of missing values, and some items were not seen as relevant by family members. Therefore, we conducted a Danish-Dutch study to develop a new measurement tool, more suitable for our population. The new questionnaire was based on both the FS-ICU and the QODD, of which six questions were used. This was done in close cooperation with the original developers. Because decision-making is a very important part of end-of-life care, we added questions about the family perceptions of the decision making process. We also included a question about the role family members wanted to play in decision-making. With these new questions, the euroQODD might add to the body of knowledge about family preferences.

This combination of the euroFS-ICU and the euroQODD is called the “European Quality Questionnaire” (euroQ2). Earlier quantitative validation showed high content and face validity [7]. In the current study we report the results of our analysis of the euroQODD part of the euroQ2 questionnaire. Our primary goal was to report response patterns from the two countries to euroQODD questions, with tests for between-country differences, and to evaluate the accessibility of the questions to respondents from the two countries. In addition, we have provided an initial evaluation of whether the instrument in its current form shows promise for identifying an underlying latent construct that represents patients’ overall quality of dying and death.

2. Methods

2.1. Instrument

The euroQ2 questionnaire (available as supplemental material) consists of two sections: the euroFS-ICU, which was completed by all participating family members; and the euroQODD, which was completed by family members of patients who died in the ICU. In this article, we report on the 14 questions that compose the euroQODD questionnaire.

2.2. Design and setting

Participants were from 21 ICUs in The Netherlands ($n = 10$) and Denmark ($n = 11$). ICUs in both countries included university-affiliated and regional ICUs, with the centers situated in different parts of the countries. This prospective study was performed during a 10-month period from October 2014 until June 2015.

2.3. Inclusion and exclusion criteria

Family members of consecutive patients who died in an ICU after a stay of at least 48 h were eligible for study participation. Up to three family members per patient (including partners, children, siblings, parents and close friends) were identified by the patient (if able) or staff during the patient’s hospitalization and received invitations to participate. Family members under the age of 18, those with cognitive impairment and those who were unable to read or write Dutch or Danish were excluded.

2.4. Recruitment of participants

Family members received oral and written information about the study and were asked for consent to participate after their loved one died. Three weeks after the patient died in the ICU, family members were sent the euroQ2 questionnaire by regular mail, together with written information and a pre-paid envelope. In the Netherlands all questionnaires were sent out by the investigators; in Denmark the

individual ICUs distributed the questionnaires. In both countries, all the completed questionnaires were returned to the investigators. If the questionnaire was not returned, a reminder with a new questionnaire was posted once after two weeks.

2.5. Patient and respondent data

Patient data were obtained from medical records and included gender, age, reason for admission (respiratory illness, cardiovascular illness, sepsis, or other condition), length of stay in the ICU, SAPS (Simplified Acute Physiology Score), SOFA (Sepsis-Related Organ Failure Score) and whether the patient received mechanical ventilation. SAPS and SOFA were available only if these scores were collected routinely by the patient’s ICU. Characteristics of family members were provided by respondents in the initial section of the euroQ2 questionnaire and included age, gender and relationship to the patient (spouse/partner, child, or other relationship).

From the original QODD six items were used. The others were judged irrelevant by Dutch family members as described previously [6]. New questions were added after interviews and expert panel reviews [7]. The euroQODD therefore consists of 14 items. Two had binary (no/yes) response options: did the patient discuss preferences for end-of-life treatment with a doctor before ICU admission, or during the ICU stay. An overall rating of end-of-life care was measured with a pseudo-continuous response scale (0 “worst care possible” to 10 “best care possible”) but only one respondent provided a rating below 5. Therefore, we merged this value with the rating of 5, and modeled the result as an ordered categorical variable with six values (5–10). The remaining items were ordered categorical variables. Five response categories described how often the patient appeared to have pain under control, to be comfortable on the ventilator, and to retain dignity: none of the time, a little bit of the time, some of the time, a good bit of the time, most of the time, all of the time. Five responses were also used to describe the extent to which the respondent agreed with decisions to limit treatment: not at all, mostly not, partially, mostly, and totally. Questions about the participants’ role in decision-making regarding continuing or limiting life sustaining treatment, had five response options: doctors without family involvement, doctors after discussion with family, joint doctor/family decision, family after discussion with doctors, family without doctor involvement. Five variables offered three ordinal response options (no, partially, yes): whether the patient received the needed emotional support, whether the patient received the needed spiritual support, whether end-of-life care was concordant with the patient’s wishes; whether the patient’s life was prolonged unnecessarily; and whether the family member had a chance to say goodbye to the patient.

2.6. Statistics

We first examined patient and family characteristics, testing for between-country differences with single-predictor regression models: probit regression estimated with weighted mean- and variance-adjusted least squares (WLSMV) for binary characteristics (gender, mechanical ventilation); robust linear regression estimated with restricted maximum likelihood for continuously-scored characteristics (age, ICU days, SAPS II, SOFA); and multinomial logistic regression estimated with restricted maximum likelihood for nominal-scale characteristics (relationship to the patient, reason for admission). We used unclustered models for patient characteristics; clustered models for family characteristics (family members clustered under patients). P -values for binary and continuous items were based on Wald’s test; those for nominal-scale variables on likelihood ratio tests. In reporting descriptive statistics for continuous measures, we used mean and standard deviation if the Shapiro-Wilk test for departure from normality had p -value ≥ 0.05 ; median and interquartile range (IQR) if the p -value was < 0.05 .

Next, we investigated the accessibility of each of the euroQODD items to family respondents, testing for between-country differences in accessibility by regressing the binary outcome (0 = no response, 1 = valid response) on country, using probit regression models.

Third, we examined (and tested for between-country differences in) valid response patterns to the individual euroQODD items. These models included adjustment for any patient or family characteristics that were associated with country at $p < 0.20$. In order to control for the number of euroQODD items compared, we used a Bonferroni correction for the number of tests (0.05/14), adjusting the level required for a judgment of statistical significance to $p < 0.004$.

Fourth, using data from the merged countries, we ran a series of factor analyses to provide an initial evaluation of whether the euroQODD instrument in its current form contains a set of items that can be combined into a unidimensional construct representing the quality of dying and death. We evaluated the fit of the resulting models with the χ^2 test of fit, requiring $p > 0.05$ for a determination of non-significant misfit of a model to the observed data. Initial models were based on merged data from the two participating countries, with subsequent testing for between-country measurement invariance. Preliminary exploratory factor analyses (EFA) of 12 of the euroQODD items (excluding two items measuring actual and preferred roles in decision-making), ruled out the existence of either a unidimensional or multi-factor model that made use of the full set of items. Beginning with the 12 items, we then ran a series of single-factor EFA models, using modification indices at each step to remove items that contributed to misfit, until an acceptably fitting unidimensional model was produced. A subsequent two-group confirmatory factor analysis (CFA) tested this model for between-country measurement invariance. Finally, we discussed methodological and conceptual problems associated with use of the current euroQODD instrument for building acceptable latent variable models.

In testing for between-country differences in response patterns, as well as in all factor analyses, we declared the euroQODD items to be categorical variables and based our conclusions on probit regression,

estimated with robust weighted least squares (WLSMV). Sample descriptives were produced with the Statistical Package for the Social Sciences (SPSS) (IBM, version 21). Between-country comparisons of patient and family characteristics and euroQODD responses, as well as factor analyses, were done with Mplus7.4.

2.7. Validity

In our previous paper on the validation of euroQ2 questionnaire we reported the clinimetric properties of the instrument [7]. A brief summary is repeated here for clarification.

2.7.1. Content validity

In the validation phase, relevance and understandability were overall very high. For the euroQODD, the median assessment of relevance was 97% (92–100%) and the median assessment of understandability was 97% (94–100%).

2.7.2. Test-retest reliability

The average test-retest agreement for the Likert scale responses in the euroQODD was 0.71 (0.53–0.83). Most of those who had changed responses from test to retest within the Likert scale had moved only one “step” up or down the scale or had moved to or from a “Not relevant” response.

2.8. Ethics

In accordance with Dutch law, the study was approved by the IRB (nWMO 21a) of Medical Centre, which was acknowledged by the institutional review boards of all participating ICU's. In Denmark, the study did not need permission from The Regional Committees on Health Research Ethics for Southern Denmark but permission to assess patient files was obtained from the Danish National Health Authorities (3-3013-353/1); the study was registered with the Danish Data Protection Agency.

Table 1
Patient and family characteristics^a.

Characteristic	Total		Netherlands		Denmark		Between-country difference ^b
	Valid n	Statistic ^c	Valid n	Statistic ^c	Valid n	Statistic ^c	
Family (total n)	217		91		126		
Age, mean (SD)	212	56.1 (14.0)	90	57.9 (13.8)	122	54.7 (14.0)	0.102
Male	212	75 (35.4)	90	34 (37.8)	122	41 (33.6)	0.526
Relationship to patient	213		90		123		0.037
Spouse or partner		79 (37.1)		42 (46.7)		37 (30.1)	
Child		99 (46.5)		34 (37.8)		65 (52.8)	
Other		35 (16.4)		14 (15.6)		21 (17.1)	
Patient (total n)	178		90		88		
Age, median (IQR)	174	73.0 (13.0)	86	73.5 (16.0)	88	72.5 (13.0)	0.939
Male	174	102 (58.6)	86	46 (53.5)	88	56 (63.6)	0.174
Days in ICU, median (IQR)	173	8.2 (12.0)	86	7.5 (10.0)	87	9.0 (13.5)	0.281
Reason for admission	174		86		88		0.135
Respiratory		76 (43.7)		37 (43.0)		39 (44.3)	
Sepsis		27 (15.5)		17 (19.8)		10 (11.4)	
Cardiovascular		48 (27.6)		25 (29.1)		23 (26.1)	
Other		23 (13.2)		7 (8.1)		16 (18.2)	
Mechanical ventilation	174	160 (92.0)	86	81 (94.2)	88	79 (89.8)	0.287
SAPS II, mean (SD)	125	59.9 (16.8)	67	59.1 (18.5)	58	60.9 (14.6)	0.551
Admission SOFA, mean (SD)	48	9.1 (3.6)	43	9.1 (3.6)	5	9.2 (3.1)	0.965

IQR = interquartile range, SD = standard deviation, n = sample size.

^a P-values shown in boldface signify variables that were used as covariates in tests for between-country differences in family respondents' answers to the euroQODD questions.

^b The tests for between-country differences were based on regression models: clustered models for characteristics of family members (family members clustered under patients) and unclustered models for patients' characteristics. Each regression model included country as the only predictor and the row variable as the outcome. The following regression types and estimators were used: for continuous outcomes (age, days in the ICU, SAPS II, and SOFA scores) linear regression with restricted maximum likelihood estimation; for unordered categorical outcomes (relationship to patient and reason for admission) multinomial logistic regression with restricted maximum likelihood estimation; for binary outcomes (gender and mechanical ventilation) probit regression with weighted mean- and variance-adjusted least squares estimation (WLSMV). P-values for continuous and binary variables were based on Wald's test; those for multinomial regressions were based on likelihood ratio tests.

^c Unless otherwise noted, the descriptive statistics presented are n(%). For continuous measures an initial test for normality was done, using the total sample; if the p-value for the Shapiro-Wilk test was < 0.05 , the median and interquartile range are presented as the descriptive statistic; if the p-value was ≥ 0.05 , the mean and standard deviation are presented.

Table 2
euroQODD questions.

QODD Aspect	TOTAL		Netherlands		Denmark		Between-country difference ^a	
	Valid n	n (%)	Valid n	n (%)	Valid n	n (%)	p ^b	p ^c
Pain under control	190		70		120			
All the time		102 (53.7)		27 (38.6)		75 (62.5)	<0.001	<0.001
Most of the time		63 (33.2)		24 (34.3)		39 (32.5)		
Good bit of the time		16 (8.4)		12 (17.1)		4 (3.3)		
Some of the time		4 (2.1)		2 (2.9)		2 (1.7)		
A little bit of the time		3 (1.6)		3 (4.3)		0 (0.0)		
None of the time		2 (1.1)		2 (2.9)		0 (0.0)		
Comfortable on ventilator	173		70		103		0.431	0.474
All the time		60 (34.7)		26 (37.1)		34 (33.0)		
Most of the time		63 (36.4)		18 (25.7)		45 (43.7)		
Good bit of the time		21 (12.1)		11 (15.7)		10 (9.7)		
Some of the time		13 (7.5)		6 (8.6)		7 (6.8)		
A little bit of the time		8 (4.6)		4 (5.7)		4 (3.9)		
None of the time		8 (4.6)		5 (7.1)		3 (2.9)		
Keeping dignity	185		73		112		0.347	0.287
All the time		94 (50.8)		37 (50.7)		57 (50.9)		
Most of the time		55 (29.7)		17 (23.3)		38 (33.9)		
Good bit of the time		14 (7.6)		6 (8.2)		8 (7.1)		
Some of the time		15 (8.1)		9 (12.3)		6 (5.4)		
A little bit of the time		6 (3.2)		3 (4.1)		3 (2.7)		
None of the time		1 (0.5)		1 (1.4)		0 (0.0)		
Emotional support for patient	159		65		94		0.837	0.918
Yes		129 (81.1)		52 (80.0)		77 (81.9)		
Partially		27 (17.0)		12 (18.5)		15 (16.0)		
No		3 (1.9)		1 (1.5)		2 (2.1)		
Spiritual support for patient	133		60		73		0.023	0.048
Yes		105 (78.9)		42 (70.0)		63 (86.3)		
Partially		24 (18.0)		15 (25.0)		9 (12.3)		
No		4 (3.0)		3 (5.0)		1 (1.4)		
Discussed preferences								
Before ICU admission	169		80		89		0.091	0.126
Yes		50 (29.6)		29 (36.3)		21 (23.6)		
No		119 (70.4)		51 (63.7)		68 (76.4)		
In ICU	94		41		53		0.422	0.342
Yes		39 (41.5)		19 (46.3)		20 (37.7)		
No		55 (58.5)		22 (53.7)		33 (62.3)		
Care concordant with wishes	154		71		83		0.953	0.614
Yes		133 (86.4)		62 (87.3)		71 (85.5)		
Partially		16 (10.4)		5 (7.0)		11 (13.3)		
No		5 (3.2)		4 (5.6)		1 (1.2)		
Life prolonged unnecessarily	204		87		117		0.925	0.878
Yes		9 (4.4)		4 (4.6)		5 (4.3)		
Partially		20 (9.8)		8 (9.2)		12 (10.3)		
No		175 (85.8)		75 (86.2)		100 (85.5)		
Chance to say goodbye	210		89		121		0.692	0.659
Yes		185 (88.1)		78 (87.6)		107 (88.4)		
Partially		17 (8.1)		6 (6.7)		11 (9.1)		
No		8 (3.8)		5 (5.6)		3 (2.5)		
Overall rating of care (0–10)	214		90		124		0.001	0.001
10		97 (45.3)		31 (34.4)		66 (53.2)		
9		62 (29.0)		23 (25.6)		39 (31.5)		
8		43 (20.1)		28 (31.1)		15 (12.1)		
7		5 (2.3)		4 (4.4)		1 (0.8)		
6		2 (0.9)		1 (1.1)		1 (0.8)		
3,5		5 (2.3)		3 (3.3)		2 (1.6)		
Decision Making								
Agreed with decision to limit LST	202		86		116		0.318	0.529
Strongly agreed		144 (71.3)		66 (76.7)		78 (67.2)		
Agreed		44 (21.8)		14 (16.3)		30 (25.9)		
Neither agreed nor disagreed		12 (5.9)		5 (5.8)		7 (6.0)		
Disagreed		1 (0.5)		0 (0.0)		1 (0.9)		
Strongly disagreed		1 (0.5)		1 (1.2)		0 (0.0)		
Actual decision-maker(s)	187		78		109		0.449	0.441
Doctor alone		15 (8.0)		10 (12.8)		5 (4.6)		
Doctor after discussing with family		66 (35.3)		20 (25.6)		46 (42.2)		
Joint decision: doctor/family		94 (50.3)		47 (60.3)		47 (43.1)		
Family after getting information from doctor		11 (5.9)		1 (1.3)		10 (9.2)		
Family alone		1 (0.5)		0 (0.0)		1 (0.9)		

Table 2 (continued)

QODD Aspect	TOTAL		Netherlands		Denmark		Between-country difference ^a	
	Valid n	n (%)	Valid n	n (%)	Valid n	n (%)	p ^b	p ^c
Preferred decision-maker(s)	192		80		112		0.361	0.345
Doctor alone		3 (1.6)		2 (2.5)		1 (0.9)		
Doctor after discussing with family		61 (31.8)		18 (22.5)		43 (38.4)		
Joint decision: doctor/family		117 (60.9)		57 (71.3)		60 (53.6)		
Family after getting information from doctor		11 (5.7)		3 (3.8)		8 (7.1)		
Family alone		0 (0.0)		0 (0.0)		0 (0.0)		

LST = life-sustaining treatment.

^a All variables were defined as ordered categorical variables, with the tests for between-country differences based on probit regression estimated with weighted mean- and variance-adjusted least squares (WLMSV) and the *p*-values based on Wald tests. All models clustered family members under patients.

^b These *p*-values are for models containing only the country indicator as predictor and the QODD aspect as the outcome. Values in boldface are those that met the cutoff for statistical significance using the Bonferroni-corrected value.

^c These *p*-values are for models that adjusted the association between country and the QODD aspect for possible confounding by the family respondent's age and relationship to the patient and for the patient's gender and reason for admission. Sample sizes for the adjusted model were reduced by 3 to 9 cases, depending upon the outcome, because of cases with valid outcome responses but missing data on one or more of the covariates. Values in boldface are those that met the cutoff for statistical significance using the Bonferroni-corrected value.

3. Results

3.1. Sample

We sent the euroQ2 to 1485 family members, of whom 1077 completed and returned the questionnaire (response rate 72.5%). Of these, 217 family members (representing 174 patients) completed the euroQODD. Respondents included 126 family members from Denmark and 91 from The Netherlands. Table 1 summarizes the characteristics of the responding family members, and demographic and ICU information about their associated patients. Family members were, on average, middle-aged, and the majority were women. Most were the patient's child (46%) or partner (37%). Patients were typically older than the family respondents, and most were men. The median length of stay in the ICU was 8 days, with a majority of the patients receiving mechanical ventilation during ICU treatment.

Table 2 summarizes responses to the euroQODD questions. In general, family members were highly satisfied with the emotional support provided to the patient, the concordance between the patient's preferences for end-of-life care and the care that was provided, and the possibilities to say goodbye to their loved one, with positive ratings from >80% of the respondents. In addition, a large majority (86%) indicated a feeling that the patient's life had not been unnecessarily prolonged. Although preferences regarding end-of-life care were discussed more frequently after ICU admission than before admission, such discussions occurred in a minority of cases at each time point, and 57.5% of the family members with valid responses to both questions indicated that such a discussion had never occurred: 50.0% in the Netherlands, and 63.8% in Denmark (data not shown). After adjustment for the family respondent's age and relationship to the patient and for the patient's gender and reason for admission, there were significant between-country differences on only two items: pain control and the overall rating of care, with family members from Denmark giving higher ratings on both aspects (*p* ≤ 0.001).

Of the 217 respondents, 212 indicated that decisions were made to limit care, and 187 gave valid responses to a question attributing the decision to doctors and/or the family. The majority (92.0%) of these respondents felt that they had been included to some extent in the decision-making process, with over half (50.3%) perceiving truly shared decision making. Of the 177 respondents who stated both their actual and preferred role, 132 (74.6%) were happy with their actual role, 32 (18.1%) would have preferred more involvement, and 13 (7.3%) would have preferred less involvement than they experienced. Almost no one (1.6%) wanted the doctor to make the decision without involving the family, and no respondents reported wanting to make the decision

themselves, without the doctor's input. A large majority (93% of those who provided ratings and for whom the question was applicable) indicated either agreement or strong agreement with the decision that was made to limit treatment.

By and large, family members had little difficulty answering the 14 euroQODD questions. In the combined samples, 81.8% of the questions received valid responses, and only 18.8% were excluded from analyses because of missing data (primarily the result of questions that were inapplicable for a family member or to which the family member didn't know the answer). However, there were four questions for which >25% of the responses were unusable: (1) patient discussion of end-of-life care preferences after ICU admission (56.7% missing, with 39.6% inapplicable [patient couldn't communicate]; 14.3% don't know, 2.8% no response), (2) provision of adequate spiritual support (38.7% missing, with 35.5% don't know and 3.2% no answer), (3) concordance between patient's care preferences and care provided (29.0% missing, with 25.3% don't know and 3.7% no response), and (4) provision of adequate emotional support (26.7% missing, with 24.0% don't know and 2.8% no answer). There were significant between-country differences in the amount of missing data on two items: pain control (23.1% missing in The Netherlands; 4.8% in Denmark) and patient discussion of care preferences before ICU admission (12.1% missing in The Netherlands; 29.4% in Denmark).

3.2. Unidimensional construct representing the overall quality of dying and death (QODD)

An initial 12-indicator unidimensional EFA model showed significant misfit to the observed data: $\chi^2 = 360.727$, 54df, *p* = 0.0000; RMSEA = 0.162, 90% CI = 0.147–0.178, probability that RMSEA ≤ 0.05 = 0.000; CFI = 0.763, TLI = 0.711. Removal of six indicators that contributed to

Table 3
Unidimensional QODD factor, standardized indicator loadings^a.

Indicator	TOTAL ^b	Denmark ^c	Netherlands ^c
Pain control	0.761	0.726	0.801
Ventilator comfort	0.817	0.711	0.890
Dignity	0.773	0.672	0.900
Spiritual support	0.765	0.802	0.711
Life not unnecessarily prolonged	0.300	0.234	0.412
End-of-life care according to patient's wishes	0.407	0.314	0.516

^a Factor analyses were based on probit regression, with all indicators declared as ordered categorical variables. All loadings were statistically significant.

^b Based on an EFA model with data from the two countries combined.

^c Standardized loadings, based on a two-group CFA model with unstandardized loadings and thresholds constrained to equality between countries.

misfit produced a six-indicator single-factor model with all loadings significant and with good model fit: $\chi^2 = 6.522$, 9df, $p = 0.6868$; RMSEA = 0.000, 90% CI = 0.000–0.061, probability that RMSEA $\leq 0.05 = 0.908$; CFI = 1.000, TLI = 1.008 (Table 3, TOTAL column).

A two-group model of the QODD construct, with unstandardized indicator loadings and thresholds constrained to equality between countries, provided evidence of between-country measurement invariance: $\chi^2 = 39.579$, 33df, $p = 0.1998$; RMSEA = 0.043, 90% CI = 0.000–0.087, probability that RMSEA $\leq 0.05 = 0.556$; CFI = 0.990, TLI = 0.991 (standardized loadings for the separate countries shown in Table 3). The two countries did not differ significantly with regard to mean levels on the QODD construct (unstandardized level for Denmark fixed at 0.000, estimated unstandardized level for the Netherlands = -0.225 , $p = 0.247$). Although all indicator loadings in both countries were statistically significant, loadings for prolongation of life and care concordant with patients' wishes were weak, with R^2 values suggesting that the latent construct explained little of the estimated variance in those variables in either country. R^2 values for the indicators in Denmark were as follows: pain control (0.527, $p < 0.001$), ventilator comfort (0.506, $p < 0.001$), dignity (0.452, $p < 0.001$), spiritual support (0.643, $p < 0.001$), prolongation of life (0.055, $p = 0.228$), and care concordant with patient wishes (0.099, $p = 0.115$). In Denmark the corresponding values were as follows: 0.641 ($p < 0.001$), 0.793 ($p < 0.001$), 0.810 ($p < 0.001$), 0.506 ($p < 0.001$), 0.170 ($p = 0.209$), and 0.267 ($p = 0.028$).

Although the QODD construct showed good fit to the data, and the demonstration of between-country measurement invariance suggested its appropriateness for between-country comparisons, it includes a type of model misspecification that is frequently made in research using structural equation modeling techniques and that is unavoidable with the current euroQODD instrument, taken alone. The model is based on the premise that the six indicators are “reflective” indicators (i.e., effects of the quality of dying and death), when they would be more accurately considered causal indicators (i.e., contributors to the quality of dying and death) [8–10]. In order for a model containing a latent variable that is measured with causal indicators to be statistically identifiable, the latent variable must have at least two outcomes (either two reflective indicators, in addition to the causal indicators, or two more distal outcomes). The euroQODD currently lacks these additional items.

4. Discussion

In this study, the euroQODD questionnaire provided relatively high overall ratings of end-of-life care for patients dying in Danish or Dutch ICUs by their family members, with very few significant differences between countries. In general, family members perceived that care was in line with patients' wishes, and only a small minority reported that life was prolonged unnecessarily. These findings are similar to those from studies that have been conducted in other countries, including the US [11,12]. Two items varied significantly between Denmark and the Netherlands with Danish participants providing higher endorsements and ratings: 1) perceived pain control; and 2) overall rating of care. This finding suggests possible opportunities for improvement in care in the Netherlands. Prior studies have identified the importance of symptom control for patients and family members [13,14], and overall assessments have been used as a reliable measure of quality of care [15–17]. However, when considering differences between countries, it is important to take into account how expectations for healthcare and healthcare providers may vary and the effect of this variability on assessments is unknown [18–21].

The high scores correlated well with previously published research on end-of-life care in general [11,12]. Previous studies suggest that support for shared decision-making may be an important factor contributing to high scores of end-of-life care [22]. Our data support this hypothesis. Both Denmark and the Netherlands have legislation and a

tradition whereby the medical team make important decisions if patients do not have decision-making capacity. Families cannot make decisions on behalf of the patient but may contribute information about patients' wishes and values. Interestingly, families' perceptions did not reflect this legislation. In the Netherlands, >60% of the family members perceived they had participated equally with doctors in decision-making while another 26% perceived that the doctor made the decision after consulting them. In Denmark, the portion of the families that felt they shared in decision-making was somewhat smaller (43%), with an additional 42% perceiving that the doctor made the decisions after consulting the family. Importantly, the majority of family members in both countries reported preferring a shared decision-making approach (slightly higher in the Netherlands at 71% compared to 54% in Denmark). Our findings suggest that relatives would like to be more involved in decision-making than they currently are. These findings support the hypothesis of an ongoing transition towards shared decision-making [23,24]. This may mark a societal shift towards shared decision-making in Denmark and the Netherlands that is not currently reflected by the laws in these countries.

We also used our data to examine whether the euroQODD (either in its entirety or with a subset of items) measures a construct representing the quality of dying and death. The original US-developed QODD survey was designed to measure six theoretical domains: symptom and personal care, preparation for death, moment of death, family, treatment preferences and whole person concerns. However, a six-factor model representing these six domains did not provide adequate fit to data from the US. Although a four-factor model using a subset of the original QODD items provided adequate fit to community data from the US [25], several of the items in that study had significant missing data in a study from Denmark and the Netherlands and were removed from the final euroQODD instrument. With the current data, we located a unidimensional construct, measured with six items, that showed good fit to the data and evidence of measurement invariance between countries. However, that construct misspecified the six items as reflective indicators. Addition of actual reflective indicators of the quality of dying and death to the euroQODD will be needed if the instrument, standing alone, is to serve as a vehicle for measuring a latent construct representing the overall quality-of-dying-and-death.

Recently, a French 15-item CAESAR questionnaire was developed and validated for use among family of critically ill patients who died in the ICU. The authors report one overall score from CAESAR with three domains: patient, interaction with and around the patient and family needs, and satisfaction [17]. Eleven of the questions are similar to the euroQODD. In addition, CAESAR includes questions about communication which we did not include in the euroQODD, although such items were included as a measure of satisfaction with care in the euroFS-ICU. In the euroQODD, questions about decision making are included which are not part of CAESAR. Low CAESAR scores were shown to correlate with higher levels of complicated grief or PTSD. We did not find an association between low scores on euroQ2 and PTSD or depression, as reported previously [7]. Further studies are needed to assess whether the overall score provided by the CAESAR is unidimensional and how CAESAR and the euroQODD or euroFS-ICU compare in order to address the call for the development of robust quality metrics to improve end-of-life care for critically ill patients [26].

Additional testing of the euroQ2 questionnaire in countries from other regions, including Southern and Eastern Europe, is currently underway. This is important for future development. Part of that testing will include adaptation of the questionnaire with additional questions that may improve the psychometric characteristics of the instrument.

4.1. Strengths and limitations

A relative strength of this study was the enrollment of > 1000 family members from two countries, of which 217 completed the euroQODD. Furthermore, family members were related to patients who were

treated in 21 ICUs of different types and located in several geographic areas, a diversity that increases the generalizability of results. The high response rate and small number of unanswered questions are additional strengths. Although response rate data is only available for the entire population and the Dutch euroQODD cohort, which are both high, these data are not available for the Danish euroQODD cohort.

There are also important limitations. Despite the high number of participants in the overall study, far fewer respondents were eligible for completing the QODD portion of the questionnaire. This smaller sample, drawn from two relatively limited geographic areas, decreases one's confidence in the generalizability of the results.

5. Conclusion

The euroQODD part of the euroQ2 project provides information about families' experiences with dying and death of their family member in the ICU. The perceived quality of end-of-life care is relatively high, and a majority of participants believed that care at the end-of-life was in accord with patient wishes. However, we identified some areas for improvement. Importantly, family members desired a higher level of participation in decision-making than they perceived occurring. There was also room for improvement in pain and symptom control. A small group of relatives found that the patient's life was unnecessarily prolonged, which may also represent an area for improvement. Psychometric assessment suggests that this version of the euroQODD warrants continued development and additional study as an outcome for palliative care interventions in the ICU. The euroQ2 – a pairing of the euroFS-ICU and the euroQODD – provides a promising new instrument to assess ICU care and identify areas for improvement.

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Conflict of interest

On behalf of all authors, the corresponding author states that there is no conflict of interest.

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